

402 Patient satisfaction in CF clinics – results from focus groups

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Objective: To identify issues important to CF-patients for being satisfied with their care in CF clinics. These issues will inform the development of a questionnaire of patient satisfaction with CF clinics.

Method: 3 focus groups with 6–8 participants each (adult patients and parents) were held in Hamburg, Berlin and Innsbruck. Overall, 3 adult men and 4 adult women with CF (21–36 years) and 12 mothers and 1 father of children with CF (10 months – 16 years) were interviewed and themes were ranked according to importance. Two focus groups were audiotaped, one videotaped. A content analysis of the transcripts was performed.

Results: The most important themes were the clinical expertise of physicians and health professionals, individualized care and treatment, the relationship between patients and health care professionals, support for coping with illness, and infection control measures. Further issues were the existence of a network of relevant health professionals, direct access to CF staff in case of questions and emergencies, and involvement of patients and parents. Overall organisation and clinic facilities were also important but not crucial to patient satisfaction. Experience with the interface between outpatient and inpatient care differs among participants.

Conclusions: Key categories of patient satisfaction with CF clinics are comparable to those of other outpatient clinics. However, we have also identified aspects that differ, mainly due to chronicity of illness such as the quality of the relationship between patient and carers and support for illness-coping. These will be incorporated in a modified, disease-specific version of the PICKER patient satisfaction questionnaire.

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404 The perceived quality of the cystic fibrosis service and the subjective dimension of the illness experience for patient's parents and caregivers: a survey method to improve the care relationship

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Introduction: express thoughts feelings and is a useful instrument in psychological adaptation processes as well as functional to promote the well being of patients, families, and cystic fibrosis (CF) caregivers. This is especially significant in the context of chronic diseases and in all the aspects of care relationship, including quality of care perception.

Aims of the study were to increase the knowledge of the CF care service, to recognize critical aspects in the relationship between patient and CF team, and to individuate psychological interventions to improve the well-being of both patients and CF caregivers.

Subjects and Methods: 105 subjects, including children's parents, 18 parental couples and 11 CF caregivers were studied from 2006 to 2008. All the subjects performed a quantitative questionnaire on objectivable quality of the service; moreover, the 18 parental couples and 11 CF caregivers underwent a qualitative interview, exploring the subjective experience related to CF. We have considered similar domains for all the involved subjects, both for quantitative and qualitative data.

Results and Conclusion: the main critical areas identified were the suitability in the multidisciplinary working team, the need of specific health resources for adults and of proper planning for overall care from childhood to adulthood, and finally the care for the whole aspects of patients' life.

In conclusion, our results suggest that the experience of narration for both patients' parents and caregivers offers a chance of sharing thoughts and elaboration about the CF patients care pathway.

403 Quality of life in children with CF and their parents

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Introduction: Recently a quality of life questionnaire was developed for children with Cystic Fibrosis (CF) and their parents. The aim of this study was to explore quality of life in children with CF, and to examine the psychometric characteristics of the Cystic Fibrosis Questionnaire in children with CF (CFQ) and their parents (CFQ-P).

Methods: 40 children with CF and their parents filled in the CFQ and the CFQ-P, between 2004–2008. Descriptives, paired t-tests and intra class correlations (ICC) were calculated.

Results: 40 children mean (SD) age 8.9(2.6), 17 boys and 23 girls, mean (SD) FEV1 85.8(21.6). Mean (SD) CFQ scores in children and parents respectively were: Physical 74.4(21.3)/ 81.4(19.7); Emotional State 79.3(12.9)/ 85.2(15.0); Eating 71.2(23.2)/ 69.2(29.8); Treatment Burden 74.6(21.4)/60.1(23.7); Body Image 85.9(19.2)/85.1(16.2); Respiratory 78.7(13.1)/84.8(12.7); Digestion 76.0(21.3)/74.7(14.2).

Paired t-test revealed significant differences between the CFQ and CFQ-P in five of the seven domains. ICC ranged from 0.25 [ns] to 0.67***.

Conclusions: Children with mild CF showed moderately decreased quality of life in seven CFQ domains. Children and proxy (parents) ratings showed statistically significant differences and low to moderate ICC's, indicating differences between perceptions of QoL in parents and children.

405 Pain in CF: a national survey on 1104 patients

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Objective: To evaluate in CF patients, pain related to the disease and procedural pain.

Methods: As part of a national project to increase awareness about pain in CF, chronic and procedural pains were retrospectively surveyed in CF patients. In 2007, questionnaires were sent to CF patients or their parents by the CF centres. Closed questions were asked about types of pain, intensity, treatment and effectiveness. Children could answer and their response was compared to their parents.

Results: 34 centres out of the 49 French CF centres took part in this study, and 1104 patients and or their parents participated. (Response rate 35%). Respondents were comparable to the French Registry population. For pain related to the disease, frequency and intensity score (analogic scale 0 to 10) of each pain are indicated in table 1. They were all above therapeutic threshold (3). Concerning procedures, 5 were above therapeutic threshold (table 2). Other procedures' intensity score such as antibiotic infusion, venous blood draw, gastrostomy care, capillary puncture, allergy (prick) tests, physiotherapy, sputum collection, TIVAD puncture were rated below 3. Patients mentioned their pain to care providers in 72% of cases for pain related to the disease and only in 52% of cases for procedural pain.

Conclusion: Pain is frequent and can be intense in CF patients. Whereas pain related to the disease is now better recognized and treated, prevention of procedural pain still needs improvement; especially as patients tend not to mention it.

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Table 1

Type of pain	Abdominal	Headache	Back	Thoracic	Joint	Costal
Frequency	79%	57%	43%	39%	35%	26%
Intensity of pain	5.2±2.1	5.2±2.2	5.0±2.1	4.7±2.2	4.9±2.3	4.6±2.2

Table 2

Procedure	Bronchoscopy	Nasopharyngeal aspiration	Blood gas	Peripheral catheter insertion	Nasopharyngeal fibroscopy
Intensity of pain	5.7±3.6	5.1±3.5	4.5±3.1	4.4±3.1	4.3±3.2